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## Exploring the Role of Occupational Therapy in Supporting Caregivers of Children with Cerebral Palsy

Kaitlyn Knecht  
*Elizabethtown College*

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Exploring the Role of Occupational Therapy in Supporting Caregivers of Children with Cerebral Palsy

By

Kaitlyn Knecht

This thesis is submitted in partial fulfillment of the requirements for Honors in the Discipline in Occupational Therapy and the Elizabethtown College Honors Program

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Thesis Director (signature required) Gina Fox, OTD, OTR/L  
4-27-2020 \_\_\_\_\_

Department Chair (signature required) Tamera Keiter Humbert, D. Ed.,  
OTR/L \_\_\_\_\_

Second Reader \_\_\_\_\_ Tamera Keiter Humbert, D.Ed.,  
OTR/L \_\_\_\_\_

Third Reader \_\_\_\_\_ Elizabeth Dalton, Ph.D., 4-30-20 \_\_\_\_\_  
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Exploring the Role of Occupational Therapy in Supporting Caregivers of Children with Cerebral Palsy

Kaitlyn Knecht

Elizabethtown College

Author's Note

This paper was prepared for Honors in the Discipline in the Occupational Therapy Department.

### **Abstract**

Caregiving for one's child is a complex occupation with a wide-reaching impact on an individual's life (Dieleman, Vlaenderen, Prinzie, & Pauw, 2019). Guardians have unique emotional needs consequent to their caregiving role but receive inconsistent treatment from healthcare professionals (Porfíro Santos Pinto, Duarte Coutinho, & Collet, 2016). This study aimed to understand the perceived psychosocial needs of caregivers of children with cerebral palsy (CP), identify support services for these caregivers and evaluate their effectiveness, and determine how occupational therapists (OTs) can most effectively address these needs.

Caregivers of children with CP engaged in semi-structured interviews to explore their perceived needs as well as facilitators and barriers to occupational performance in meaningful life roles.

Responses were coded and analyzed for themes and trends and organized through the lens of the Person-Environment-Occupation Model. Participant data showed a sense of obligation to care for their child, pressure to maintain a sense of emotional strength, generational coping differences, and disinclination to utilize support groups. OTs must individualize caregiver interventions to cooperatively address each caregiver's unique mental health experience.

## **Introduction**

There are over 10 million children with complex medical needs in the United States as of 2006, and the prevalence of childhood disability increased 15.6% from 2001 to 2011, indicating that this number is only increasing (Houtrow, Larson, Olson, Newacheck, & Halfon, 2014; Kuo, Cohen, Agrawal, Berry, & Casey, 2011). The World Health Organization (WHO) estimates that worldwide, there are 18 million children (15 years or younger) who require caregiving support (WHO, 2017). These children require increased medical care and support for function in their day to day activities, and often this caregiving role falls to the child's parent(s), especially to mothers (Pedrón-Giner, Calderón, Martínez-Costa, Borraz Gracia, & Gómez-López, 2014). Caregivers of children with chronic conditions have specialized needs which differ from caregivers of adults; therefore, it is imperative that healthcare professionals understand the unique needs of this population in order to implement the most client centered interventions and supports (Chi & Demiris, 2015).

While there exists a variety of chronic conditions that can affect children, cerebral palsy (CP) is the most common motor disability among children in the United States (Centers for Disease Control and Prevention [CDC], 2019). The CDC (2019) estimates that one in 323 children has CP. CP is more common among boys than girls and is more common among African American children than among Caucasian populations. Seventy-seven-point-four percent of children with CP have spasticity, but 58.2% can walk independently. Thirty-one percent use adaptive equipment for mobility. Forty-one percent have comorbid epilepsy, and 6.9% have comorbid Autism Spectrum Disorder (CDC, 2019). Many parents become caregivers for their children with CP, creating a need for healthcare professionals to address their psychosocial needs (Rentinck, Ketelaar, Jongmans, Lindeman, & Gorter, 2009).

## Literature Review

### Impacts of Caregiving

Caregiving is a broad term which can hold many different connotations for a given individual. Jones, Hocking, & Wright St-Clair (2010) suggest that no two people understand their caregiving role in precisely the same way, and no two people are affected by their caregiving role in the same way. Therefore, healthcare professionals must seek to understand each individual's operational definition of what caregiving means to them personally (Jones et al., 2010). These definitions may be affected not only by personal perception, but also by culture and nature of the diagnosis, so it is important for the healthcare professional to ask probing questions to fully understand each caregiver's individualized conception of their role (Jones et al., 2010; Rentinck et al., 2009).

**Positive impacts.** Although negative impacts are the most common focus of the literature, family members across the lifespan have expressed several positive outcomes of taking on a caregiving role. When asked about positive outcomes of their caregiving role, caregivers of aging adults reported finding great value in companionship (Cohen, Colantonio, & Vernich, 2002). Many explained that they found caregiving to be a rewarding and enjoyable task, focusing on the impact they made on their loved one's quality of life. Still others felt they were fulfilling a duty to serve their loved one and felt useful when helping to make decisions regarding their care (Cohen et al., 2002). Parents of adolescents with cerebral palsy (CP) explained that becoming involved in their child's medical care as a caregiver opened access to a new social network of other parents who served as caregivers for their children, where they found support and meaningful friendships (Dieleman et al., 2019). Parents also reported that the friends they had before their child's diagnosis who supported them through the course their



child's disability grew even closer and dearer to them (Dieleman et al., 2019). Parents also felt strongly loved by their communities as family and friends gathered to give support when children were hospitalized (Dieleman et al., 2019).

Some parents also reported increased strength in familial bonds after the adoption of a caregiving role (Dieleman et al., 2019). Still others reported that it is highly rewarding to see their child benefit from interventions the parents have been trained to carry out or from a specific healthcare service that the parent worked to arrange, because it makes them feel they have succeeded in serving their child well (Dieleman et al., 2019). Some parents also place higher value on religious faith and morality as a response to their circumstances and consciously choose to embrace a positive attitude towards life (Larson, 2010; Tzoufi et al., 2005). Some caregivers explained that the bonds between members of their immediate family were strengthened in the years following their child's diagnosis (Larson, 2010). Larson argues that positive framing of the caregiving experience is incredibly beneficial to overall mental health status for caregivers by framing the child's disability as "part of the ordinary, rather than the tragic" (2010, p. 37).

**Negative impacts.** Caregivers also report negative impacts of caregiving, and much of the literature focuses on these aspects of the caregiving experience. When asked generally about their experiences, caregivers rarely organically identify positive impacts of their role, mentioning positive impacts after prompting (Cohen et al., 2002). Many studies neglect to ask after positive impacts of caregiving specifically, and therefore their data is negatively skewed (Cohen et al., 2002). Negative impacts of caregiving identified in the existing literature can be categorized into impacts on physical health, mental health, family quality of life, social participation, and finances (Dieleman et al., 2019; Larson, 2010; Porfírio Santos Pinto, Duarte Coutinho, & Collet, 2016; Tzoufi et al., 2005).

**Physical health.** Many caregivers experience problems with their physical health due to their role as a caregiver. In their systematic review, Chi & Demir (2015) found that 17% of caregivers report a physical limitation that impedes their ability to care for their loved one adequately. Tzoufi et al. (2005) found that parents of children with epilepsy and other chronic neurological conditions expressed decreases in their overall physical health after taking on a caregiving role. Parents of children with chronic conditions other than epilepsy, such as cerebral palsy, showed greater reductions in physical health than parents of children with epilepsy (Tzoufi et al., 2005). The authors do not offer an explanation for this difference, but note that the care of a child with cerebral palsy is more complex than caring for a child with epilepsy due to the physical limitations involved (the child may struggle with ambulation or mobility) (Tzoufi et al., 2005). Therefore, it is logical that a caregiver who is responsible for providing physical assistance with transfers and ambulation experiences increased physical strain.

**Mental health.** In a study comprised of caregiving mothers of children with neurological diseases and home enteral nutrition, researchers found that caregiving mothers are at increased risk of psychological distress compared to the general population (Pedrón-Giner et al., 2014). The researchers attribute this to the increased stressors inherent to daily life: the act of providing constant, complex care; the amount of time that must be dedicated to caregiving; and the task of feeding the child. This particular kind of stress is the strongest predictor for both emotional and physical health problems, particularly among caregivers of children with chronic conditions (Pedrón-Giner et al., 2014). Caregivers who displayed a high amount of symptoms of anxiety and/or depression also showed a more negative affect, increased presence of intrusive negative thoughts, and a heightened fear response “disproportionate” to the triggering stimuli (Pedrón-Giner, 2014, p. 394).

Dieleman et al. (2019) similarly found that caregivers of children and adolescents with cerebral palsy have heightened risk of diminished general well-being and increased psychosocial issues. Dieleman et al. (2019) asserted that this is due to parental need for “autonomy”, social “relatedness,” and a sense of “competence” in the care of their child, and the threat to fulfillment of these needs presented by adoption of a caregiving role (p. 208). Parents whose child has been diagnosed with a disease with a very poor prognosis have special challenges with feelings of low competence: they feel “powerless” (Dieleman et al., 2019, p. 211). As parents are forced to adjust their expectations for their child’s functioning, they may also have to reevaluate their role as a parent given their child’s disability (Dieleman et al., 2019).

Parents often experience feelings of deep grief, akin to mourning the death of a loved one, when confronted with the perceived loss of their child’s health and expected future prospects (Rentinck et al., 2009). This is termed ambiguous loss. If negative emotions are carried forward for years following the diagnosis, parental interactions with and hope for the child are negatively affected (Rentinck et al., 2009). Counseling can be incredibly useful for dealing with ambiguous loss, but parents can be hesitant to be vulnerable by discussing their problems (Tzoufi et al., 2005). Tzoufi et al. (2005) found that parents of children with chronic neurological diseases such as epilepsy were less likely than the general population to discuss personal struggles and are less likely to voice their ideas honestly and openly in the home, corresponding to heightened levels of familial conflict. This affects the functioning of the entire family.

***Family quality of life.*** Porfírio Santos Pinto et al. (2016) asserted that the introduction of chronic disease into a family creates “vulnerability” (p. 503). Throughout a series of interviews with caregivers, the researchers found that receiving a diagnosis for a chronic condition deeply impacts the emotional stability of the whole family, to the point of sending them into “shock,

crying spells, and even depressive crises” (Porfírio Santos Pinto et al., 2016, p. 503). Dieleman et al. (2019) found that caregivers often spend so much time caring for their child that they no longer have any time left for recreation or leisure, or even time left to spend with their spouse. This places additional strain on a relationship that is already under stress from caregiving.

***Social participation.*** According to Tzoufi et al. (2005), social-emotional factors can often be more stress- and distress-inducing for parents than their child’s diagnosis. Tzoufi et al. (2005) found that parental social involvement is affected by their child’s specific diagnosis. In their study, the researchers identified that parents of children with epilepsy experienced higher levels of social interaction than parents of children with other neurological conditions (Tzoufi et al., 2005). Specifically, the researchers identified that families of children with cerebral palsy have very limited social opportunities due to their child’s motor impairments (Dieleman et al., 2019; Tzoufi et al., 2005).

Motor impairments can limit accessible locations and often make it more difficult to travel even short distances to meet up with family and friends. Motor impairments can also make it difficult to maintain friendships with the parents of the child’s friends involved in sports teams and other physical activities as peers outpace the child’s motor abilities and move on to more advanced activities (Dieleman et al., 2019). Tzoufi et al. (2005) also acknowledge the possibility of social stigma as a mediating factor between motor impairments and family opportunities for socialization.

Pedron-Giner et al. (2014) found that caregivers have limited social opportunities because they simply lack time. Caregivers in their study had the task of home enteral nutrition feeding in addition to standard caregiving tasks (Pedron-Giner et al., 2014). Standard caregiving tasks might include supervising for safety, helping the child complete activities of daily living,

speaking regularly with medical experts to manage care, and coordinating health services or advocating for approval of a specific service (Dieleman et al., 2019; Jones et al., 2010). The daily tasks of caregiving amounted to nearly the time required for a full-time job. These caregivers reported that they simply did not have enough time for socialization with peers left in their day after doing the things necessary for their child's wellbeing (Pedrón-Giner et al., 2014).

Dieleman et al. (2019) offer additional support for this claim. In their study, they found that parents of children and adolescents with cerebral palsy reported feeling socially isolated and having few friends due to the amount of time they spent working on intensive healthcare for their child. They also found that caregivers feel socially isolated because their lives are so different from those of their peers that they no longer know how to relate to one another's life experiences. Their friends and sometimes family tend to make inappropriate comments or minimize the child's disability and its impact on the family out of lack of understanding, making parents feel isolated and undervalued, like nobody understands their experience (Dieleman et al., 2019). Other friends unintentionally isolate caregivers by making them feel pitied. "We lost a lot of friends," one mother admitted to Dieleman et al. in an interview (2019, p. 210).

Dieleman et al. (2019) also propose another reason for parental social isolation. Using the Self-Determination Theory of social development established by Deci & Ryan (2000), Dieleman et al. (2019) found that caregivers experience social isolation due to internal conflict and feelings of inadequacy regarding their own "autonomy," need for "relatedness," and "competence" (p. 205). The researchers argue that denial of the chance to exercise psychological autonomy, explore opportunities to find relatedness among peers, and experience opportunities to demonstrate competence in achieving personal goals results in feelings of "pressure or obligation, social alienation or loneliness, and personal failure" (Dieleman et al., 2019, p. 205).

In their study, Dieleman et al., (2019) identified that caregivers of children with disabilities often experience barriers to fulfillment of all three of these psychological needs, exacerbating social isolation.

Parents also find themselves under stress as the mediators of their child's social life (Jones et al., 2010). Jones et al. (2010) assume parental responsibility to prevent social isolation for the child and offer suggestions on how to do so. The researchers found that this is a particularly difficult task due to the amount of "time and effort" required to help others understand the child's diagnosis and behaviors and that this same lack of understanding undermines parental support structures (Jones et al., 2010, p. 11).

***Financial Implications.*** Many parents also encounter financial concerns due to the additional expenses incurred by their child's medical care. Tzoufi et al. (2005) found that all families included in their study (families of children with epilepsy and other chronic neurological conditions) experienced financial burdens related to their child's care. Interestingly, the researchers found a disparity in the amount of financial stress experienced between the diagnoses. Tzoufi et al. (2005) found that families of children with chronic neurological conditions other than epilepsy experienced more financial strain than families of children with epilepsy. The researchers attribute this to the complexity of the diagnosis. They set forth children with cerebral palsy as an example: these children not only need medical care in the form of physician visits and medications, but also might require therapy, adaptive equipment, accessible transportation, or even home modifications in order to function in their daily lives. By contrast, the researchers postulate that children with epilepsy and without comorbid conditions might only need doctor's visits and medications to manage their symptoms. Therefore, the family with the child with cerebral palsy has an increased financial burden due to the complexity of their child's

needs (Tzoufi et al., 2005). The CDC (2019) estimates the lifetime healthcare costs for a person with cerebral palsy to \$1 million.

Tzoufi et al. (2005) do not, however, downplay the financial strain placed on families of children with less complex needs, citing several sources demonstrating that families of children with epilepsy also experience financial burden. Larson (2010) found that many families experience financial strain due to having a limited or single income. She found that 54% of a heterogeneous sample of caregivers of children with complex care needs reported having enough money to live without worry of running out of money (Larson, 2010). However, this indicates that 46% of caregivers in the sample had such significant financial constraints that they had to worry about finding the money to care for their families.

Often, parents of children with chronic conditions find themselves unable to leave the child alone or with another possessing less expertise in the child's care, limiting their ability to find and maintain full-time employment (Jones et al., 2010). The problem of unskilled help is exacerbated by a shortage of home care nurses qualified to care for children with complex medical needs (Kuo et al., 2011). For families in which both parents are present, this issue may result in one parent taking a full-time job while the other, most often the mother, stays home as the primary caregiver (Pedrón-Giner et al., 2014). In single-parent households, this may present as a single parent struggling to hold down a job while still providing the necessary care for their child with a disability and for their other children.

Caregiving often affects one's career. Pedrón-Giner et al. (2014) estimate that the amount of time the caregivers in their study spend attending to their children's medical needs is approximately the same required for a full-time job. Naturally, this incredible time commitment precludes some caregivers from being able to work as much as they might like or need to support

their family and pursue their career. Pedrón-Giner et al. (2014) found that the mothers in their sample had both an educational level and an unemployment rate higher than that of the average Spanish female population. This indicates that these women, while competent and well-educated, lack the logistical ability to seek competitive employment due to the demands of caregiving (Pedrón-Giner, 2014).

Kuo et al. (2011) found that over half of the families in their study expressed financial concerns or the loss of employment. Although legislation is in place to protect families with children with disabilities from financial crisis, such as the Family Medical Leave Act (FMLA), Kuo et al. (2011) found that these resources are often underutilized. Chung et al. (2012) found that employers are underinformed regarding these benefits, and parents reported the benefits were insufficient to meet their needs. The parents in this study also noted that the process of applying for these benefits is complex and long, and that they found themselves so overwhelmed by their child's care needs that they did not have the time or cognitive energy to find information regarding benefits and carry out the process of applying. This problem was especially exacerbated during times of medical crisis, yet times of medical crisis are when parents are most in need of supports like the FMLA. Parents in Chung et al.'s 2012 study identified a lack of adequate support from healthcare professionals in navigating this process and suggested that hospital and clinic staff could offer tangible support for application processes.

**Mediating relationships between positive and negative impacts.** Cohen et al. (2002) sought to understand the relationship between positive and negative impacts of caregiving. In their study involving 289 caregivers, they found that 73% could express at least one positive impact of caregiving. As they analyzed the data further, a pattern emerged: the researchers observed an inverse relationship between positive and negative impacts. The more positive ideas



a caregiver was able to identify about their caregiving experience, the less negative impacts they reported. In this study, the negative impacts assessed included caregiver depression, caregiver burden, and self-assessed health (Cohen et al., 2002). This finding has far-reaching clinical significance because these three negative impacts are shown to have a direct positive relationship to mortality risk for the caregiver and institutionalization for the family member receiving care (Cohen et al., 2002). Clinicians can use this information to guide caregivers in framing their experiences positively as a protective factor against negative impacts and their correlates. Cohen et al. (2002) indicate that further research is required, since their study is not designed to ascribe any causality in the relationship between positive and negative impacts and can only indicate correlation.

Larson (2010) identified several factors which impact a family's self-reported life satisfaction and psychological well-being. She noted that caregivers' personal factors such as adaptability to new situations and demands, ability to find balance among competing priorities, and overall health of family functioning impact a caregiver's overall well-being and life satisfaction self-reports. The presence of these factors identified by Larson (2010) may serve as a foundation which allows caregivers to recognize positive impacts of their experiences.

### **Interventions for Caregivers**

As healthcare professionals provide care for children, it is just as important to provide care for the parent. The following section explores interventions healthcare professionals might employ in interactions with parent-caregivers.

**Provider interactions and education.** Porfírio Santos Pinto et al. (2016) conducted a series of interviews with caregivers of children and determined that stress over their child's medical struggles makes them a highly vulnerable population, especially when they are called

upon to directly confront their child's medical status. Thus, they are often at their most vulnerable when they are in contact with healthcare professionals. This necessitates delicacy and compassion in healthcare professionals' interactions with caregivers. Porfirio Santos Pinto et al. (2016) emphasize that healthcare professionals must take care to "humanize" their interactions with caregivers, favoring warm caring over cold clinical language (p. 504). This is also a key concept of health literacy: people understand little and remember less during times of high stress, especially if the concepts are complex (Smith, Floerke, & Thomas, 2016). This makes parents of children in medical distress especially vulnerable to misunderstanding or simply not remembering a physician's instructions, which could compromise the health of their child.

***Receiving a diagnosis.*** Receipt of a diagnosis marks an especially stressful moment in a caregiver's life (Porfirio Santos Pinto et al., 2016). Often, the family has spent months or years visiting physicians from varying specialties in different hospitals, perhaps even in different states, trying to find someone who can fully understand their child's symptoms and give them a diagnosis. In Porfirio Santos Pinto et al.'s study (2016), several interviewees reported being bounced from one hospital to the next as physicians struggled to find someone more qualified than themselves to make a diagnosis, and one shared, "it's been eight years of struggle but so far no one has a complete diagnosis" (p. 501). Often, parents feel that their concerns are going unheard or that they are not being taken seriously by healthcare providers (Dieleman et al., 2019). Both positive and negative interactions with healthcare professionals during this time shape the way caregivers view the healthcare system moving forward and affect their long-term coping. It is the responsibility of healthcare professionals to offer support for the parent as well as the child during this period of emotional crisis (Porfirio Santos Pinto et al., 2016).

Upon finally receiving a diagnosis, there is relief at having an answer to all the child's symptoms, but it opens parents to new stressors. With a diagnosis comes a prognosis which may not be comforting. Parents are often confronted with statistics indicating that they will outlive their child. One interviewee admitted (Porfirio Santos Pinto et al., 2016, p. 503),

the only fear I have is not because he has the disease, [but] because the comments is that this disease doesn't reach 12 [years]. I fear that I'm raising my son, educating my son, to death, you know? I'm afraid of that.

Parents who do not receive a terminal diagnosis for their child can still experience difficult emotions following diagnosis. They may, for the first time, be receiving confirmation that their child's symptoms will persist for the rest of their life—that the disease is chronic. This can result in parental shock, inability to stop crying, and even depressive crises (Porfirio Santos Pinto et al., 2016). "I'm taking [anti-depressive] medication but it's not working because my problems are bigger than me," one interviewee explained (Porfirio Santos Pinto et al., 2016, p. 503).

In their 2019 study, Dieleman et al. found that receipt of a diagnosis allows parents to begin to move forward. Having a diagnosis gives them an idea of what to expect for their child and allows them to begin restructuring their ideas about their child's and their own future, to begin to process the implications of what their child's disability means for the family. Some of the interviewees even saw the diagnosis as an opportunity for catharsis, saying that being able to finally come to terms with a diagnosis allowed them to begin looking to the future again instead of being caught in the desperation of each moment while trying to figure out how to explain their child's symptoms (Dieleman et al., 2019). Dieleman et al. (2019) do not, however, underrepresent the difficulty of coming to terms with a diagnosis: their interviewees expressed feelings of guilt, failure, and anger alongside their relief at having a diagnosis. As one participant

expressed, “The most difficult period that we had was...when we had to accept that our child has a disorder” (Dieleman et al., 2019, p. 212).

Dieleman et al. (2019) emphasize the importance of healthcare professionals taking the time to make sure parents feel heard and valued during the process of searching for a diagnosis. In light of the immense stress surrounding receiving a diagnosis, Porfirio Santos Pinto et al. (2016) recommend that healthcare professionals address parents’ mental health at the time of diagnosis and take the time to fully, clearly explain the child’s prognosis to avoid confusion or misconception regarding the child’s future. Dieleman et al. (2019) assert that healthcare professionals should ask questions regarding parents’ immediate problems following diagnosis, but also about their concerns for the future. Neither study found that the healthcare systems in their scope were adequately fulfilling these responsibilities. Future concerns may include worry about how to pay for the child’s care, how to find secure the services the child needs, and who will take care of the child when the parent can no longer do so. Parents are often too afraid to broach these topics without prompting from healthcare professionals, but it is better for their mental health to discuss them proactively (Dieleman et al., 2019). Above all, healthcare professionals must keep their interactions with caregivers respectful, compassionate, and humanizing to support them through times of vulnerability (Porfirio Santos Pinto et al., 2016).

***Healthcare transitions.*** In a scoping review analyzing studies that covered transitions from the neonatal intensive care unit (NICU) to Special Care Nursery (SCN), Ballantyne et al. (2017) determined that healthcare transitions are a point of great stress for families. This is due to parental exclusion from decision-making processes, lack of sufficient information provided to parents in preparation for the transition, and the loss of a familiar setting of care in exchange for a setting with less individual attention. Ballantyne et al. (2017) emphasized that healthcare

professionals must be open and honest in all communications with parents and that parents must be kept informed as a key part of all decision-making regarding their child. They also discussed the importance of forming a bond akin to friendship with parents to provide emotional support and reduce stress for parents in this time of uncertainty. The healthcare professional's role, Ballantyne et al. (2017) assert, is to support the parent in their role as the primary caregiver. In a study examining the transition between the NICU and developmental/rehabilitation services among parents of children with CP, Ballantyne et al. (2018) showed that healthcare professionals should focus on helping parents understand what to expect from the new environment, feel supported throughout the transition process, and organize their resources so they do not have to worry about logistics and can focus on emotional coping.

***Individualization of interventions.*** In their study, Petty, Jarvis, & Thomas (2019) found that caregiving is a profoundly emotional experience that no two individuals experience in quite the same way, and therefore, all interventions conducted with caregivers must also be individualized. In a study with 200 parents, Feudtner et al. (2015) found that in order to best support parents through the difficult decision-making processes common to caregiving, healthcare professionals must first understand each individual parent's concept of what it means to be a good parent. Understanding each caregiver's good-parent beliefs is key because it frames how they interpret what is best for their child. This affects medical decision-making and the parent's commitment to carrying over interventions into the home as necessary. For parents who have just received a prognosis for their child that forces them to change the way they think about their child's future, understanding good-parent beliefs is crucial to helping parents cope with their own emotional turmoil while supporting their child (Feudtner et al., 2015).

As previously established, focusing on positive aspects of caregiving is a protective factor against negative impacts such as depression (Cohen et al., 2002). The researchers advocate that healthcare professionals should take the time to help each caregiver process their emotions regarding their caregiving experience. By discussing the whole of the caregiving experience—both positive and negative—with parents, the healthcare professional allows them time to process their emotions in a safe and nonjudgmental space. The healthcare professional can also guide the parent to the realization of positive aspects of their experience through probing questions and helping the parent reframe their experience. This can be cathartic and help the parents embrace the positive aspects of caregiving that they may not have previously considered (Cohen et al., 2002).

***Family inclusion in interventions.*** It is critical to make the parent part of the care team (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Petty et al., 2019). Parents have an inherent right and a psychological need to be involved in their child's care (Larson, 2010). Incorporating a parent fully into the care team might include educating them on their child's diagnosis and how to protect themselves while caring for the child. This might include anything from instructing caregivers on safe body mechanics for transfers to providing resources for counseling and offering coping strategies (Adelman et al., 2014). In these discussions, it is important to keep communications empathetic rather than clinical in order to make the parent feel valued as an individual (Petty et al., 2019). It is also of utmost importance to keep communication with parents open and honest (Ballantyne et al., 2017).

Caregivers must be kept informed and up to date in their own child's care, both for the sake of their role as a member of the care team and for their role as a parent. Parents have the right to participate and have the final say in all healthcare decision-making processes, but

healthcare professionals are responsible for ensuring they have all the information and guidance they need to make these decisions wisely (Ballantyne et al., 2017). Since mothers are most commonly the primary caregiver, fathers are often overlooked in communications regarding their child's care, but inclusion of the father is key (Ballantyne et al., 2018).

There are a few differences between how healthcare professionals can best support fathers and mothers. While both fathers and mothers expressed a need for information regarding their child's diagnosis and prognosis, fathers are more likely to seek out information individually, while mothers are more likely to ask for information from healthcare professionals (Ballantyne et al., 2018). Fathers have more difficulty finding peers who understand their circumstances and often feel that support groups are designed with mothers in mind. Fathers also expressed the emotional burden of feeling responsible to suppress their own emotional turmoil in order to be strong for mothers (Ballantyne et al., 2018). Rather than focus inward on their emotions, fathers turn their focus outwards to outcomes of treatment, and many cope by finding recreational activities that their whole family can participate in together (Ballantyne et al., 2018). Healthcare professionals should keep these gender differences in mind while supporting parents; while a mother might benefit from a support group, a father might reap greater benefit from a suggestion on how to adapt basketball so his child can participate with his or her siblings. Once again, it is important to understand the individual parents and their values to know how to best support their needs.

***Multidisciplinary support.*** Caregiving is an occupation that touches all areas of a parent's life. Positive and negative impacts on physical and mental health, family quality of life, social participation, and finances have been explored. This is too large an aspect of a parent's life for one healthcare professional to adequately address on their own, as Pedrón-Giner et al. (2014)

recognize. They call instead for multidisciplinary support to help relieve the psychological and other burdens of caregiving. This indicates that any healthcare professional in contact with caregivers has a responsibility to assess the caregiver's physical and mental health status as well as the child's status.

***Institutionalized changes.*** Given the body of research indicating the responsibility of healthcare professionals to address caregiver burden and failure of existing systems to offer adequate support, several researchers call for institutional reforms to allow greater space and time to be dedicated to caregiver support. Petty et al. (2019) assert that as early as the NICU, hospitals should begin establishing a good relationship with parents and addressing their emotional needs as part of the normal functioning of the NICU, just as they address the physical needs of every baby in the NICU.

Kuo et al. (2011) recommend that families receive one-on-one training on the child's care before discharge from the hospital to ensure the child's safety at home. Adelman et al. (2014) call for physicians to continue to assess caregiver health each time they see the care recipient at their practice.

Adelman et al. (2014) observe that caregivers are more likely to neglect their own health and deprioritize preventative health measures and offer the practical suggestion of issuing a caregiver burden screening tool to caregivers while the care recipient is treated and asking the caregiver to make their own doctor's appointment at the same time they make a follow-up for the care recipient. These measures would help remind caregivers of the importance of their own health and hold them accountable to more regular check-ups with doctors (Adelman et al., 2014).

Pedrón-Giner et al. (2014) also suggest that all healthcare professionals, not just physicians, should administer periodic caregiver mental health screenings to monitor caregiver



psychological health. Some advocate for a wider reform as well. Kuo et al. (2011) calls for a reorganizing of the healthcare system to provide families with increased access to community-based nonmedical supports such as respite care to alleviate caregiver stress. Increased access to such services could potentially allow parents more freedom to go to work, support groups, and physician appointments; to see friends; or even to go grocery shopping or run to the drug store to pick up their child's medications.

### **The Role of Occupational Therapy**

As healthcare professionals serving as a point of regular contact with caregivers, occupational therapists (OTs) have a responsibility to address parental wellbeing (Larson, 2010). Larson (2010) provides guidelines for OTs helping parents process their emotions related to caregiving, demonstrating that OTs must help parents positively frame their experiences. After adopting a caregiving role, parents often feel as though they have lost control of their circumstances and cannot even protect their own child. This undermines many parents' self-perception as a good parent, leaving them with feelings of guilt and failure (Dieleman et al., 2019; Feudtner et al., 2015). Therefore, Larson (2010) explains, it is important to help parents establish a sense of internal locus of control regarding their own mental health. Most importantly, the therapist must remain nonjudgmental of the parent, creating a safe space for the parent to process their thoughts and feelings without fear of rejection (Larson, 2010). While discussing caregiving with parents, it is crucial to understand each individual parent's perception of what caregiving means to them as the foundation of the conversation (Jones et al., 2010). This prevents miscommunications and makes the parent feel heard. This is of particular importance because many parents have reported feeling overlooked and their opinions undervalued (Dieleman et al., 2019).

Jones et al. (2010) also note the usefulness of short-term goals (goals that are small and achievable within a short timeframe) in helping parents see tangible progress in their child's functioning and restoring hope for their child's future. Jones et al. (2010) remind readers that OTs can assist with other facets of the parent-child relationship as well, ranging from recommending behavior management approaches to assisting the parent in finding opportunities to increase their child's integration into the community. Dieleman et al. (2019) outlines how therapists can support parents in building supportive social networks and coach parents through advocating for their child's needs. OTs can help parents practice explaining their child's diagnosis and its implications to friends and family and give tips on how to help others gain a more concrete understanding of what it is like to stand in the caregiver's shoes.

OTs have a role in health literacy and are therefore well equipped to help parents better understand their child's medical information (Galati et al., 2018). Before and upon discharge from a hospital, OTs are responsible for helping parents understand what to expect from therapy both in the hospital and in the home (Ballantyne et al., 2018). OTs can also assist in the coordination of healthcare services (Porfirio Santos Pinto et al., 2016).

OTs often find themselves administering therapy in families' homes. This presents a uniquely delicate situation (Mayes, Cant, & Clemson, 2010). Many parents perceive the home as a sort of sacred space for family intimacy—a place for warmth and comfort, a place of physical and emotional safety. Healthcare professionals entering this sacred space can disrupt this intimacy by medicalizing the home. Mayes et al. (2010) urge clinicians to take great care to avoid violating the meaning ascribed to places in the home and to be sensitive to the emotional repercussions of making space for medical interventions within the home. This is equally important in deciding where in the home to hold therapy sessions as it is in making

recommendations for accessibility if the child requires adaptive equipment for mobility. The therapist must respect that they are in a home rather than a facility and consider the impact that their presence as a medical professional has on members of the family (Mayes et al., 2010).

### **Caregiver Perspectives on Efficacy of Interventions and Supports**

Of the many studies regarding caregivers of pediatric clients, few have asked after their perceptions of areas of strength and need in their experiences with healthcare professionals. Petty et al. (2019) found that parents of children in the NICU found that parents reported mostly positive things about the healthcare professionals with whom they interacted (75% of data collected). Parents described healthcare professionals as “supportive and empathic,” “saviors” of both the baby and the parent (p. 1917). Parents emphasized that good healthcare professionals invested not only in meeting their physical needs, but also their emotional needs (Petty et al., 2019). By contrast, parents in the study who reported negative experiences with healthcare professionals (25%) noted that their ideas and concerns were being overlooked; that communication between staff was poor, resulting in failure to keep parents informed and/or giving parents conflicting reports; and that they found themselves in conflict with healthcare professionals rather than supported by them. These complaints indicate areas in which healthcare professionals need to improve care delivery (Petty et al., 2019).

### **Problem Statement and Research Questions**

The literature clearly indicates that as healthcare professionals in regular contact with caregivers, occupational therapists have a responsibility to address caregiver wellbeing (Dieleman et al., 2019; Jones et al., 2010; Larson, 2010; Mayes et al., 2010). The CDC’s national survey has established CP as the most common motor disorder among children in the United States, indicating a large body of caregivers for these children (2019). OTs are well equipped to

help these caregivers (Larson, 2010). The literature shows that interventions must be individualized to understand and accommodate each caregiver's unique experience, but there is limited research focusing on caregivers' expressions of their perceived needs (Petty et al., 2019). Therefore, this study seeks to gain a better understanding of the perceived needs of caregivers of children with CP in order to identify how OTs can best support them. This study seeks to learn:

1. What are the perceived emotional and/or psychosocial needs of caregivers of pediatric clients with CP?
2. From what services are caregivers receiving support, and are these services both effective and sufficient to meet their perceived needs?
3. How can OT most effectively address the perceived needs of parents of children with CP?

### **Methodology**

This exploratory study utilized a qualitative interview approach in order to explore the perceived needs of caregivers of children with CP and ways in which OT can address these needs. Qualitative interviews allow for the researcher to obtain thick description of participants' daily experiences and understand the meaning and values through which participants interpret these experiences (Taylor, 2017). This format was suitable for identifying participants' perceived needs and strategies to meet these needs. Prior to participant recruitment, this study was approved by the Elizabethtown College IRB as an expedited review.

### **Participants**

Participants were recruited through purposive sampling, a form of sampling in which the researcher selects participants with special knowledge or experience in a given area, such as caregiving (Etikan, Musa, & Alkassim, 2016). A purposive sampling technique was selected to

ensure that participants would be able to offer information pertinent to the study's research questions. Inclusion of participants was determined by the following criteria: 1) the participant was currently a caregiver of a child (age 1-21) with cerebral palsy, 2) the participant was 18 years of age or older, 3) the child was currently receiving or had received OT services and other services as needed for at least two months prior to the study, and 4) the caregiver spoke English as a first language.

Participants were recruited through flyer advertisement (Appendix A) via two venues, including a closed online support group for parents of children with CP and a local sports league for children with physical disabilities. The flyer included information regarding the purpose of the study, an overview of study procedures, and contact information for the student researcher. Prospective participants then contacted the researcher using the contact information provided on the flyer.

### **Data Collection**

Data were gathered through semi-structured interviews with each participant. A semi-structured approach was selected to enable the researcher to guide conversation towards the research questions and create fixed points for comparison across interviews while also allowing the researcher to explore in greater depth the experiences unique to each caregiver (Taylor, 2017). Interview questions (Appendix B) were created based on an extensive review of the literature on caregiving and the research questions. The researcher rehearsed interview questions with a faculty mentor prior to conducting interviews with participants. When prospective participants contacted the researcher, the researcher explained the details and procedures of the study in greater detail and obtained a verbal preliminary consent. Interviews were scheduled at a time convenient to the participant and were conducted over videoconferencing or telephone call

depending on the participant's preference. The researcher provided the informed consent (Appendix C) to participants, and participants returned the signed copy via email prior to the beginning of each interview.

Interviews were audio recorded and transcribed verbatim. A secure, online speech to text platform was used to assist with transcription, and the researcher reviewed the digital transcriptions to ensure accuracy and de-identify all confidential information included in the interviews.

### **Data Analysis**

Each interview transcript was coded and emerging themes were identified by the researcher and by the faculty mentor. The researcher and faculty mentor reviewed and coded all interviews individually and then collaborated to triangulate client interview data. This process of researcher triangulation increased the trustworthiness of the data because it eliminated researcher bias and presuppositions (Taylor, 2017). Related themes were grouped together to deepen understanding of related phenomena and grouped themes were organized through the lens of the Person-Occupation-Environment (PEO) Model. The PEO Model allows for a holistic understanding of human experience by incorporating aspects of a person, including their values and abilities; the person's daily activities and occupations; and the person's physical, temporal, social, cultural, and virtual environments (Wong & Leland, 2018). Its wide view of factors affecting a person's performance in their desired occupations makes the PEO Model valuable to occupational therapy, and its focus on client-centeredness make it particularly appropriate for use with caregivers (Gibbs, Boshoff, & Lane, 2010). The PEO Model was selected for use in this study for its client-centeredness and its applicability to the data shared by participants.

Data were kept strictly confidential. After interviews were transcribed, electronic copies were stored in a folder on the researcher's password-protected laptop. The student researcher and the faculty advisor had sole access to the data. After the completion of research, virtual data and audio recordings were deleted.

## Results

### Participants

In total, 4 participants agreed to join in the study and complete semi-structured interviews (Table 1). All participants served in a parent or grandparent role and were caregivers for children ranging in age from 4-14 years old. Of note, Participants 2 and 3 were a married couple who cared for the same child.

Table 1.

#### *Participant Demographics.*

Participant	Role	Age of Child	Child's Diagnoses	Years of Caregiving
Participant 1	Mother	4 years	PDCD*	4 years
Participant 2	Grandmother	14 years	CP and ASD	12 years
Participant 3	Grandfather	14 years	CP and ASD	12 years
Participant 4	Grandmother	12 years	CP resulting from infancy TBI	12 years

*Note.* Summary of demographics of participant and the child for whom they serve as a caregiver.

\*CP is a feature of PDCD.

PDCD: Pyruvate dehydrogenase complex deficiency.

ASD: Autism Spectrum Disorder.

TBI: traumatic brain injury.

### Interview Results

Consistent with the PEO model, concepts which emerged from the interviews were categorized into personal, environmental, and occupational factors. Participants identified

personal and environmental factors that affected their caregiving experiences and described how occupations serve as coping mechanisms.

**Personal Factors.** All participants emphasized that taking on a caregiver role completely changed their lives. They stressed the heavy emotional impact of caregiving, both positive and negative. Participants also expressed the ways in which accepting a caregiver role has changed their roles and expectations for their life.

***Emotional responses.*** Participants expressed mixed emotional responses to the caregiving experience. Participants acknowledged positive feelings as well as feelings of intense stress and pressure.

***Positive responses.*** Participants expressed a deep bond with their child and a sense of honor and moral affirmation stemming from their role as a caregiver. This sense came from a variety of factors, including spending increased time with their child, leaving paid employment, and the amount of emotional energy that has been devoted to the child's care over the years. Participant 4 explained, "Just the fact that he's still here...I'm privileged to be his grandma...He's a little miracle man." This perspective that the child is a gift to the caregiver was prevalent in Participant 1's interview as well.

Participants 2 and 3, however, focused more on the sense of moral affirmation they derived from their caregiving roles. "[Taking on a caregiving role] was the right thing to do," Participant 3 said simply. Participants specifically emphasized that seeing their own influence on their child's development and quality of life is encouraging and affirming. The knowledge that their own actions directly improved their child's life was a major motivator for all participants, encouraging them to persevere in their caregiving roles.



*Negative responses.* While participants expressed positive emotional responses to caregiving, they also shared that caregiving adds a feeling of stress and pressure to their lives. Participants expressed concern not only for the welfare of their child with CP, but also for other family members. They related that they feel strained from working to keep the family together amidst the stress of caregiving. Participant 1 illustrated this concept by stating, “I’m constantly building up this sense of ‘it’s okay’...I just really have to be that strong person for everybody. And sometimes it’s just like, it’s hard.” All participants also expressed that some family relationships have become strained as a result of their caregiving role. While participants still generally keep in touch with family members, their relationships have transitioned to more of a working relationship rather than an emotionally fulfilling one. As Participant 4 recognized, “Our relationship has deteriorated from all this, as mother-daughter.” In addition, the responsibilities of a caregiver role often make traveling to see family members difficult, as the needs of the child are complex and hard to manage with long travel. Participants 2 and 3 shared their frustration over their inability to visit their children and grandchildren: “[Caregiving has] completely affected our lives.”

Participants also experienced stress from a sense of obligation to care for their child compounded by the difficulty of locating resources and supports for caregiving. Participant 2 explained, “We got a kid whose life depends on us...We took on the responsibility and we’re trying to see it through...but if we could just [get help]!” Participant 3 shared that he and Participant 2 adopted a caregiving role out of a sense of moral duty to their grandson with the expectation that they would receive support in caring for him. Now, they feel abandoned by a system that does not have time for them.

Participants also expressed significant stress and anxiety regarding their child's future. Looking to a future day when they would no longer be able to provide the child's care due to their own aging, some participants felt unequipped to find replacement care for the child. They expressed that the resulting uncertainty is a major source of daily stress. They also shared their fear that no one else is capable to provide for their child as well as they do. "I just don't trust individuals until I really know that they get the whole picture of [my child]," explained Participant 1. "I don't know where she would be if I couldn't do it [care for her]."

**Changes in life roles and expectations.** Acceptance of the caregiving role itself was cause for great stress for participants because it necessitated the rearranging of other life roles and expectations. Participants continue to struggle with the ongoing process of adapting to new expectations for life.

**Changes to life roles.** Participants listed an array of new roles that they have adopted since becoming a caregiver as well as changes in the expression of preexisting roles. Participants most notably found themselves in a new role as advocate for the child in their care. Participants emphasized that they were immediately made the central figure in their child's care: coordinating care, finding resources, researching information, and identifying potential treatments and interventions. As their children aged, participants expanded their advocacy to include classroom inclusion, adaptive equipment, and therapy services. Participants felt the need to advocate to secure their child's best interest, fearful that without their input, their child's quality of care would be greatly diminished.

Participants struggle to find a balance between caregiving and other roles. Participants related the exhausting difficulty they experienced attempting to navigate their roles as (grand)parent to their child with CP, (grand)parent to other siblings, caregiver, spouse, and

working adult. Participant 1 found that she could not fulfill all these roles in a meaningful way, so she left her job as a teacher to be a full-time caregiver for her daughter. Some participants have found a balance of parenting and caregiving by setting distinctive boundaries for each role. They designate times of day for caregiving activities and times to focus on other roles, such as (grand)parent or spouse. “[Setting boundaries] gives us that...breathing room,” Participant 1 explained. Participants 2 and 3 had a similar difficulty in negotiating a balance between responsibilities as caregivers and as spouses. “We used to do everything together and now we do separate things,” Participant 2 stated. Their grandchild requires consistent supervision, so they take turns participating in leisure activities and taking trips to see family because their grandchild does not tolerate long travel, leaving little time to spend together. They have yet to find a reliable and satisfying balance between their roles as caregivers and spouses.

Participants have found ways to adapt the expression of their preexisting roles to fit with their lives as caregivers. Since Participant 1 left her job as a teacher, she has started leading Sunday School at her church as a way to continue teaching. Although she left her job as a teacher behind, she still uses those skills every day with her child. “I’m still a teacher,” she said with a smile. “I’m like [my child’s] teacher.”

Participants 2, 3, and 4 were grandparents who returned to a parent role when they accepted a caregiving role. They expressed how they had thought that part of their life was behind them, and that the adjustment to helping someone with daily activities such as toileting and dressing felt like a major developmental regression in their life. While learning to accept a parent role, they simultaneously grieve the loss of their expectations for their roles as individuals at or near retirement.

*Changes to life expectations.* Participants 2, 3, and 4 experience an ongoing grief process for the loss of their expectations for their retired lives. “This is my time of life,” Participant 4 stated, “I should be travelling and enjoying life.” Instead, participants found themselves unable to perform the basic leisure or social participation activities in which they used to engage frequently. “We can’t do what we want to do when we want to do it. Ever,” expressed Participant 2. Looking at the bucket list she had made with her husband, she could see that “as long as we have [our grandchild], there’s just things we’re not going to be able to do.” Since they expect to be caregivers for their grandchild until they physically cannot continue, they realize that their lives will be drastically different than how they imagined as a result of their caregiving role. The tension between loss of expectations for life and obligation to care for their child is a source of great internal distress for Participants 2 and 3.

As a much younger individual, Participant 1 also experienced loss of expectations for her life, but she makes an ongoing effort to positively reframe the experience. Rather than focusing on the loss of family vacations and images of the ideal family experience, she has adopted a perspective of slowing down and simply experiencing life as it comes each day. She finds a sort of peace in dropping out of the “rat race” in which she previously found herself. When she struggles to let go of her expectations, she assures herself, “We’ll do that later.”

In addition to loss of expectations for their own lives, participants expressed grief for the loss of expectations for their child’s life. “I just sometimes think like, what, what—what would she be like if she could do those things...like if she was able to walk and run, like, what would that be like for us?” Participant 1 shared. Looking back at old family photos, attending preschool with her daughter, and spending time with her friends and their young children all remind Participant 1 that her child’s development is taking “a different journey.” Participant 2 similarly

shared that a visit with her other grandchildren revealed “just...how much we do for [our grandson].” This ambiguous loss made it difficult for her to return home after the visit because she so wished that her grandson could have more functional independence.

### **Environmental Factors**

Environmental factors of the healthcare system and of American culture affected participants’ caregiving experiences. Positive and negative factors emerged as reducers of or contributors to overall stress load.

**Factors of the healthcare system.** Participants had varied experiences navigating the environment of the healthcare system and finding support from their child’s healthcare team. All participants found that level of support varied by individual provider.

***Positive experiences.*** Participants shared that members of their child’s healthcare team, including physicians and therapists, not only provided information on their child’s care and diagnosis, but also offered other resources, including referrals to support groups, strategies for behavior management, and perhaps most importantly, personal emotional support. In addition, they described how members of their child’s team further positively impacted them by always viewing the child as an individual person rather than as a patient with a disability. “Treat him like an intelligent 14-year-old kid,” advocated Participant 3. Participants also cited community resources and organizations as being helpful in finding resources for obtaining adaptive equipment and identifying financial supports such as waiver programs.

***Negative experiences.*** Participants’ negative experiences can be grouped into two categories: therapeutic interactions and infrastructural concerns.

***Therapeutic interactions.*** While participants voiced positive interactions with their healthcare team, some participants also struggled to communicate effectively with their child’s

therapists or doctors. They attributed this difficulty to lack of consistency among providers, busy schedule of therapy team, and lack of effort from the team: Participant 4 cited that she did not have contact information for her grandson's school therapists, and Participants 2 and 3 noted month-long gaps in response time to emails. All four participants stated that they had very little education regarding their child's diagnosis and/or deficits when they first brought the child home. "They told me, 'He has some delays.' That's all they said," Participant 2 recalled. Later in her daughter's treatment, Participant 1 recounted an unmanageable influx of information from healthcare providers. "I was so overwhelmed...I was just like, I didn't know what to do first. I didn't know what to do second," she recalled.

Participants expressed difficulty in establishing rapport with their child's therapists. Participant 1 had a negative experience with a PT early in her child's treatment resulting in injury, leading to a hesitancy to trust new therapists. She prefers to be hands-on in her child's treatment. All participants similarly expressed that they have difficulty learning to trust new therapists due to the high turnover rates with the therapists working with their child.

*Infrastructural concerns.* Participants expressed dissatisfaction with existing infrastructural support systems. They have found that it is more difficult to find support for children with higher care demand, resulting in a system in which the caregivers with the greatest burden have the least opportunity for respite from caregiving. Participant 4 perceived a gap in supports for children with CP specifically: many of the camps and day programs she has investigated for her grandson exclude children with CP.

As aging caregivers, Participants 2, 3, and 4 also voiced concerns regarding future plans for their child once they can no longer serve as a primary caregiver. They have received little support in their search for future care. "Maybe [providers] stay away. I think they're just sick of

hearing [from us] right now,” Participant 3 said. Participants have rarely received referrals to useful agencies. “I have to fight, but...I’m the one that finds the programs...This has probably been the hardest thing I’ve done ever in my life, is getting help for him,” Participant 4 explained. Participants also expressed concerns over the expense of programs and limited availability of waivers to alleviate costs.

**Cultural factors.** Participants shared how cultural stigma surrounding disabilities has affected their experiences as caregivers. Participant 4 expressed a protective anger towards adults who look at her grandson as though he is different or other but shared that she invites children to ask questions and learn that her grandson is just like them, just with some disabilities. She believes it is very important to teach the next generation to accept those who are different than themselves to combat the stigma she currently encounters.

Participant 1 stated that she has experienced little conscious bias against herself or her daughter, but that people tend to assume that her daughter cannot participate in activities due to her physical limitations, so they do not invite her to try. This has resulted in feelings of social isolation for Participant 1. She hypothesized that people might exclude her and her daughter because they perceive that it is too difficult, for Participant 1 or for themselves, to adapt activities so her child could participate. “I think sometimes they don’t do it intentionally,” she said, but she still feels separate, labelled as a “mom of a child with a different journey.”

### **Occupations as Coping Mechanisms**

Participants identified individualized occupations that helped them cope with the stress of caregiving. Participants emphasized leisure and social participation, spirituality, and mental health management as crucial coping occupations.

***Leisure and social participation.*** Participants self-identified leisure and social participation occupations as coping mechanisms to handle the stress of caregiving. Each participant selected leisure occupations suited to their own individuality and interests. Participants found a balance of solitary and social leisure occupations. Solitary leisure occupations afforded participants the opportunity to care for their own mental health. “It was so nice...to do something for myself,” Participant 1 recalled. Participants have also found social leisure occupations to be a source of “rejuvenation,” as Participant 1 stated. All participants preferred to depend on networks naturally formed around common leisure interests as a source of social support rather than utilizing support groups or other stereotypical caregiver resources. “I was able to get what I needed emotionally from other people on similar journeys,” Participant 1 said. Participant 4 also raised the practical concern that she does not have time for support groups, focusing her time on her grandchild’s care.

***Spirituality.*** Some participants identified their faith a source of resilience. Church provides a break to “pray and think,” as Participant 1 explained. Participant 4 attributed her patience with her grandson to God’s influence in her life. “I just was made to have children,” she stated. This belief was central to her sense of self and provided intrinsic motivation to continue caring for her grandchild despite her stress and frustration.

***Mental health management.*** Participants self-identified cognitive coping strategies to help mitigate stress and increase their own self-efficacy. Some participants practiced mindfulness techniques. “My motto is ‘one day at a time,’” Participant 1 stated. She explained that maintaining focus on the present prevents her from being overwhelmed by the future uncertainties that she cannot control. Instead, she focuses on immediate, solvable problems,



thereby increasing her own self-efficacy. Participants also utilized deep breathing techniques to combat stress.

Although participants have found some successful coping mechanisms, they have also adopted some maladaptive coping strategies. Over the course of her interview, Participant 1 realized that she defaults to avoidant coping strategies. “I honestly don’t like talking to you about it,” she said. “It’s not something I really think about much because it hurts sometimes to think about it.”

### **Discussion**

This study aimed to understand the perceived psychosocial needs of caregivers of children with CP, identify support services for these caregivers and evaluate their effectiveness for meeting these needs, and determine how OT can most effectively address these needs.

Participants in this study experienced a wide array of emotions, most prevalently stress and anxiety. Feelings of stress and anxiety are consistent with the literature on the emotional toll of caregiving (Dieleman et al., 2019; Pedrón-Giner et al., 2014). Participants experienced stress and anxiety from two sources: intrinsic stress and extrinsic stress. Intrinsic stress is stress derived from the participant’s role as a caregiver. Intrinsic stressors identified by participants include strained familial relationships, their sense of obligation to their child, fear for their child’s future prospects, ambiguous loss of their child’s abilities, changes in role expression, and financial difficulties. Stress stemming from familial strain, financial concerns, fear for the child’s future, and ambiguous loss are consistent with those identified for pediatric caregivers in the literature (Dieleman et al., 2019; Rentinck et al., 2009; Tzoufi et al., 2005). Participants’ sense of obligation to their child, need to balance familial roles, and adoption of an advocacy role are less prevalent in the literature.

Extrinsic stress is derived from external sources and encompasses participants' descriptions of the effect stigma has had on their caregiving experience. Participants encountered stigma from close family as well as from the general public, and both resulted in frustration and increased stress levels for participants, as is consistent with the literature (Tzoufi et al., 2005). Continual exposure to intrinsic and extrinsic factors results in cumulative stress, which predisposes individuals to depressive symptoms and Major Depressive Disorder (Vinkers et al., 2014). Long-term stress and anxiety can also result in caregiver burnout. Healthcare professionals should monitor cumulative stress and potential caregiver burnout regularly in their interactions with caregivers.

Participants identified Early Intervention therapists, local agencies, private aides, and personal social networks as their primary sources of support. While participants verbally reported having an adequate amount of emotional support, participants were noted to express frustration, stress, and anxiety throughout their interviews, which may indicate signs of caregiver burnout (Truzzi, Valente, Ulstein, Engelhardt, Laks, & Engedal, 2012). The discrepancy between participants' perception of their own mental health and their symptomology may indicate that participants do not feel confident approaching the healthcare team to discuss their emotions without prompting from a healthcare professional, as is seen in the literature (Tzoufi et al., 2005). Their hesitance to express their negative emotions may also be due to their self-identified sense of duty to be the emotional stronghold of the family. Healthcare professionals must also take care to create a safe space in which caregivers feel comfortable sharing their emotions. In order to accurately assess caregiver mental health, healthcare professionals may find they need to directly ask a caregiver how they are doing emotionally, whether they feel they can manage their stress, and what assistance the professional can offer. OTs are well prepared to provide this

support due to their training in mental health; extensive knowledge of informal assessment; and experience in removing barriers to health, wellness, and occupational performance (American Occupational Therapy Association, 2016).

While interviews did not directly address it, some difference in coping approaches were noted between parents and grandparents. The younger participant exhibited a more positive outlook combined with an avoidant coping strategy, while the older participants seemed to have a more direct focus on their grandchild's needs and the loss of their own life expectations. This indicates that different generations may prefer different coping strategies. This insight may be helpful in guiding healthcare professionals' assessment of and interventions for caregivers' mental health. These apparent generational differences may be considered relative to one's therapeutic use of self and communication style when providing education or family training to caregivers (Taylor, Lee, & Kielhofner, 2010). It should also be considered that the older participants have been caregiving for a longer period of time, so increased cumulative stress load may have affected their coping strategies over time. The discrepancy may also be a function of the level of support services available for the child or caregiver success at navigating the healthcare system, since older participants expressed a need for greater infrastructural support.

Literature cites support groups as beneficial and commonly suggested interventions for caregivers (Oliver et al., 2017). However, all participants in this study preferred natural, preexisting, or self-selected support systems to the artificial environment of a support group. This suggests that healthcare professionals must provide individualized interventions for caregivers. While the importance of individualization is upheld by the literature, support group referrals remain a standard treatment for caregivers (Feudtner et al., 2015). OTs are well equipped to develop and implement individualized caregiver intervention plans suited to fit their

preferences and emotional needs. For caregivers who feel uncomfortable in support group settings, OTs can work with them to identify existing supportive social networks or develop new networks in a way that feels natural to them. OTs might suggest forming social networks around common interests, as some participants in this study did. OTs can also assist caregivers in development of individual coping strategies, since participants in this study developed some unhealthy or avoidant coping strategies without the guidance of a healthcare professional.

### **Limitations and Future Research**

This study included a small sample size of participants recruited from one geographic area, making it difficult to fully generalize results to all caregiver populations. In addition, this study focused solely on caregivers for children with CP. Some participants in the study cared for children with CP and a comorbid condition, so this difference may have contributed to additional stressors less prevalent among caregivers of children with CP only. Interviews were conducted during the 2020 Coronavirus pandemic, which may have resulted in disproportionately high caregiver anxiety and stress levels.

Future research may also explore differences between the experiences of male and female caregivers. More research is needed to better understand how the occupation of caregiving changes across the lifespan as a child ages into adulthood. Research may also be conducted with caregivers for children with diagnoses other than CP to identify similarities and differences in their experiences and understand how a child's diagnosis might impact the caregiver experience. Future research may also aim to understand the role of OT with pediatric caregiver support and investigate efficacious interventions for pediatric caregivers.

### **Conclusion**

Caregiving for one's child is a complex occupation with a wide-reaching impact on an individual's life. Each individual experiences caregiving differently, identifying both positive and negative impacts of their caregiving role. This research has the following implications for OT practice:

- Caregivers have unique emotional needs, including mental health concerns of cumulative stress, anxiety, and depression risk.
- OTs should maintain open communication and family-centered care to reduce caregiver stress and support self-efficacy.
- OT should incorporate individualized caregiver interventions into their regular treatment of pediatric clients to address a caregiver's unique experience.
- OTs must directly ask caregivers about their mental health to give caregivers opportunity to share their emotions.
- OT interventions should address on a caregiver's greatest sources of individual stress and include cooperative creation of coping strategies that work for each caregiver.

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## Appendix A

# share your story

OPPORTUNITY TO PARTICIPATE IN A  
RESEARCH STUDY WITH ELIZABETHTOWN COLLEGE

### WHAT'S BEING STUDIED?

The role of the caregiver is incredibly important. Parents take on responsibility for countless aspects of their child's wellbeing, and healthcare professionals rely on parents greatly for support with home care and maximizing their child's independence. However, healthcare professionals often fail to offer adequate support to caregivers. In this study, I want to hear your stories, understand what caregiving means for you, and learn how occupational therapists (OTs) can better offer support to caregivers like you.

### WHAT WILL THIS STUDY LOOK LIKE?

You have the opportunity to sit down for a face-to-face interview or we can schedule a time to talk over the phone or through a video conferencing app. I would love to understand how caregiving has affected your life and how OT can help support you through the tasks of caregiving. I am looking to understand:

- How do parents understand caregiving?
- What are their needs as caregivers?
- What services have been offered to caregivers, and have they been helpful?
- How can OT most effectively offer support to caregivers specific to their identified areas of need?

### HOW CAN I GET INVOLVED?

If your child is between ages 1-21, has a diagnosis of cerebral palsy, and is receiving or has received OT services for at least 2 months, this study is for you! If you would like to be interviewed and lend your experiences to this study, contact Kaitlyn Knecht, Elizabethtown College Occupational Therapy Student, at [knechtk@etown.edu](mailto:knechtk@etown.edu). We can talk more about the study if you have questions, or we can set up an interview time.

If you know someone else who has a child with cerebral palsy and would like to be interviewed, feel free to pass my information along!

### QUESTIONS?

Contact Kaitlyn Knecht, OTS, B.S. 2020 & M.S. 2021  
[knechtk@etown.edu](mailto:knechtk@etown.edu) | (717) 831-6322

This study is conducted under the guidance of Dr. Gina Fox, OTD, OTR/L.

## Appendix B

1. Demographics:
  - a. How old is your child with cerebral palsy?
  - b. How many children do you have?
  - c. What therapy and other healthcare services has your child received?
  - d. How long has your child been receiving these services?
2. Tell me about your experience with raising a child with CP.
  - a. Tell me about \_\_\_\_\_. What's he/she like? What's your favorite thing about being his mom/dad? What does he/she have challenges with?
  - b. Do you do anything differently now/how has your routine changed? What is one of the hardest things about being his mom/dad/grandma/grandpa?
3. Who on the healthcare team was the first one to educate you on \_\_\_\_\_'s diagnosis?  
Who explains changes in care, and does it make sense?
4. Have any healthcare professionals been able to offer you meaningful support with [struggles mentioned in 2b]?
  - a. If so, who? When? What did they do?
    - i. Is there anything you've done apart from their suggestions?
    - ii. Did it help?
  - b. How did you address it on your own?
  - c. What kinds of things do you do to manage your stress?
5. It sounds like you've really been working with a whole team since \_\_\_\_\_ was born. If there was one thing you could change about how healthcare professionals interact with you and \_\_\_\_\_, what would it be?

- a. That makes a lot of sense. Is there anything else you would want to change?
  - b. *If it comes up:* From my own experience growing up with a sister with epilepsy, did you ever feel like the healthcare team was addressing you as a person or did you feel labelled as a caregiver rather than a valued individual?
6. What's your most positive interaction with a member of \_\_\_\_\_'s care team? Is that something you wish the other people on his care team would do?
7. We've talked a lot about the whole health team, but you said he's receiving OT. What sorts of things are they doing in OT sessions?
  - a. Is there anything you wish your child's OT could help with? Or, is there anything you wish your child's OT would have helped with?
  - b. Does the OT include you in the sessions? Do you wish they would include you more or keep you more in the loop?
8. Do you have any advice for a parent who's just starting out?

## **Appendix C**

### **Consent Form**

Title of Research: Exploring the Role of Occupational Therapy in Supporting Caregivers of Children with Cerebral Palsy

Principal Investigator(s): Kaitlyn Knecht, OTS and Gina Fox, OTD, OT R/L

#### Purpose of Research:

The purpose of this study is to determine the perceived emotional and/or psychological needs of caregivers of children with cerebral palsy, to determine the usefulness of existing supports for caregivers, and to identify how occupational therapy can most effectively address the perceived needs of parents of children with cerebral palsy.

#### Procedures:

As a participant, I will engage in an interview with the student researcher to share my experiences as a caregiver. The interview will take place face-to-face in a private location of my choosing or can take place over the phone or via video chat. My responses to interview questions will be audio recorded, but all information will be kept protected and confidential. Audio recordings will be transcribed verbatim, and transcriptions will be analyzed for common themes and recurring factors.

#### Risks and Discomforts

I understand that there are minimal to no risks or discomforts anticipated from my participation in this study. I might feel slightly uncomfortable at times when discussing my personal

experiences with caregiving; however, I understand that all my responses will be kept confidential. The student researcher will make every effort to help me feel comfortable. If there is a question I do not feel comfortable answering, I can choose to skip that question.

### Benefits

I understand that this study will have no direct benefits to me; however, the information I provide may, in the future, help healthcare professionals to better understand how to best support caregivers of children with cerebral palsy.

### Compensation

I understand that I will not receive any compensation for participating in this study.

### Confidentiality

The information gathered during this study will remain confidential with all records to be kept private and locked in a file during the study. Only the researchers listed on this form will have access to the study data and information. The results of the research will be published in the form of an undergraduate paper and may be published in a professional journal or presented at professional meetings. In any report or publication, the researcher will not provide any information that would make it possible to identify me.

### Withdrawal without Prejudice

My participation in this study is strictly voluntary; refusal to participate will involve no penalty. If I initially decide to participate, I am still free to withdraw at any time.

Contacts and Questions

If I have any questions concerning the research project, I may contact Kaitlyn Knecht at (717)831-6322 or Dr. Gina Fox at (717)891-7670. Should I have any questions about my participant rights involved in this research I may contact the Elizabethtown College Institutional Review Board Submission Coordinator, Dr. Kyle Kopko at kopkok@etown.edu.

**Statement of Consent:**

- ☐ I am 18 years of age or older.
- ☐ I have read the above information. I have asked questions and received answers.
- ☐ A copy of this consent form has been provided to me.

Participant Signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator Signature \_\_\_\_\_ Date \_\_\_\_\_